

STATE OF WASHINGTON

WASHINGTON STATE BOARD OF HEALTH

1102 SE Quince Street • PO Box 47990 Olympia, Washington 98504-7990

February 11, 2003

The Honorable Alex Deccio, Chair Senate Health & Long Term Care Committee 213A Newhouse Building Post Office Box 40414 Olympia, Washington 98504-0414

Dear Senator Deccio:

We are writing as members of the State Board of Health to share the Board's support for Senate Bill 5421, an act relating to newborn hearing screening.

Washington's newborn screening law (Chapter 70.83 RCW: Phenylketonuria and Other Preventable Heritable Disorders) delegates authority to the State Board of Health to determine which disorders in addition to phenylketonuria (PKU) are to be included in newborn screening required by the state. The statute also delegates authority to the Department of Health (DOH) to require screening tests of all newborn infants before they are discharged from the hospital for the detection of the disorders that are defined by the State Board of Health. Current regulation (Chapter 246-650 WAC: Newborn Screening) requires screening for four disorders; PKU, congenital hypothyroidism, congenital adrenal hyperplasia and hemoglobinopathies such as sickle cell disease. Chapter 246-650 WAC is currently open for review by the State Board of Health.

The State Board of Health, in conjunction with the State Department of Health, engaged in a deliberative process to evaluate what, if any, additional disorders should be considered for required newborn screening. Board Member Dr. Tom Locke and State Health Officer Dr. Maxine Hayes co-chaired the Newborn Screening Advisory Committee. Advisory committee members included a broad range of experts representing medical specialists, hospitals, public and private insurers, parents, local public health officials, and child health advocacy groups.

The Newborn Screening Advisory Committee recommended that the Board use specific criteria to evaluate any disorders for newborn screening. The criteria fall into five categories: (1) prevention potential and medical rationale, (2) treatment availability, (3) public health rationale, (4) available technology and (5) cost-benefit/cost-effectiveness. The advisory committee used these criteria to recommend that the Board add six additional disorders for mandatory newborn screening, including newborn hearing.

The Board accepted the Newborn Screening Advisory Committee recommendations as part of the Board's consideration of amendments to Chapter 246-650 WAC. The Board asked the

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Department of Health to incorporate the committee's recommendations for the six additional disorders into its FY 2003-05 budget development process. The Board also determined it would not consider final changes to the newborn screening rule until after the Legislative adopted the final budget for Fiscal Year 2003-05. At this time we are aware that Governor Locke intended to include the full costs of newborn hearing screening in his proposed FY 2003-05 budget.

The Board will not act on any changes to the current regulation (Chapter 246-680 WAC--Newborn Screening) until after the Legislature completes its work. At that time, we will consider newborn hearing screening along with the other recommended disorders in light of scientific evidence and budget realities.

Our overarching concern is that each candidate condition for inclusion in Washington's mandatory newborn screening program be considered on its own merits in order to assure that all of Washington's newborns have their best chance at a healthy, productive future.

Thank you for your consideration.

Lenda Lylce

Sincerely,

Linda Lake

Chair, Washington State Board of Health

Thomas Locke, M.D., M.P.H.

Member, Washington State Board of Health Co-Chair, Newborn Screening Advisory

Committee

cc: Senate Health & Long Term Care Committee Members

Senator Betti Sheldon

Representative Ruth Kagi

Ms. Ree Sailors, Governor's Office of Health Policy

Dr. Maxine Hayes, State Health Officer

Ms. Patty Hayes, Department of Health

Washington State Board of Health Members

Mr. Don Sloma, State Board of Health